

The Manitoba First Nations Centre for Aboriginal Health Research: Knowledge Translation with Indigenous Communities

Manitoba First Nations Centre for Aboriginal Health Research: l'application des connaissances dans les communautés autochtones

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Abstract

Knowledge translation at the Manitoba First Nations Centre for Aboriginal Health Research emerged through several population health research initiatives conducted in partnership with Canadian Indigenous peoples. An initial collaboration to carry out a regional health survey laid the foundation to share leadership, power and decision-making, and resulted in a program to build capacity in the First Nations health planning community through familiarity with the tools and skills of health researchers. Connections between health researchers and First Nations health planners have since led to the incorporation of evidence-based decision-making in many First Nations communities.

Résumé

L'application des connaissances au *Manitoba First Nations Centre for Aboriginal Health Research* [centre des Premières nations pour la recherche sur la santé des Autochtones du Manitoba] découle de plusieurs initiatives de recherche sur la santé de la population menées en partenariat avec les peuples autochtones canadiens. Une première collaboration, dans le cadre d'une enquête régional sur la santé a permis de jeter les fondements d'un partage du leadership, des pouvoirs et du processus décisionnel, et a mené à la création d'un programme visant à renforcer les capacités des planificateurs des services de santé des Premières nations par la familiarisation avec les outils et les compétences des chercheurs en santé. Les liens de collaboration entre les chercheurs et les planificateurs en santé des Premières nations ont, depuis, mené à un processus décisionnel fondé sur l'expérience clinique dans plusieurs de ces communautés.

KNOWLEDGE TRANSLATION (KT) AT THE MANITOBA FIRST NATIONS Centre for Aboriginal Health Research (MFN-CAHR) involves the exchange, synthesis and ethically sound application of knowledge in a complex set of interactions among health jurisdictions, Indigenous groups, researchers, policy makers, program developers and healthcare service providers. MFN-CAHR's commitment to KT grew out of several population health research initiatives conducted in full partnership with Canadian Indigenous peoples.

Historically, First Nations health planners and service providers did not have access to trustworthy health information based on the best available research. Most health information was housed within universities and governments, which were inaccessible to First Nations communities. In the mid-1990s, MFN-CAHR and the Assembly of Manitoba Chiefs (AMC) entered into a research partnership with the Assembly of First Nations to implement the provincial component of the national First Nations Regional Longitudinal Health Survey.

A key KT product of this survey was the First Nations Applied Population Health Research Summer Institute, which introduced population health research approaches to First Nations healthcare directors and providers. Together, these initiatives contributed to new research and KT networks dedicated to reducing health disparities in First Nations communities in Manitoba.

The KT Initiative

The partnership struck to carry out the regional health survey laid the foundation to share leadership, power and decision-making from design to KT. The survey was successfully launched and achieved a high response rate.

At the dissemination stage of the survey, MFN-CAHR and AMC realized that First Nations health directors and providers would greatly benefit from an opportunity to work directly with the survey data to answer policy-related questions for their tribal areas and communities. Funding was secured from Health Canada's National Health Research and Development Program, and MFN-CAHR and AMC successfully offered the First Nations Applied Population Health Research Summer Institute for one week each summer over three years to First Nations health planners. The goal of the institute was to build "receptor" capacity in the First Nations health planning community through familiarity with the tools and skills of health researchers. Additionally, the institute sought to increase First Nations' interest in using the survey results by modelling the process of answering complex health policy questions through the process of data analysis. For example, participants were asked to develop questions that they thought their communities would like to have answered (e.g., "Who is most at risk for diabetes in the community?"), and then survey and provincial health data were analyzed in a workshop format to answer such questions.

Today, MFN-CAHR and affiliated researchers and partners are engaged in a wide range of research activities designed to benefit Indigenous communities. Research now extends across the four pillars of the Canadian Institutes of Health Research (CIHR) – biomedicine, clinical practice, health systems and services, population and public health – and reflects a strong participatory relationship with Indigenous communities in Manitoba, Canada, North America and internationally. Specific CIHR-funded projects include biomedical and clinical studies of diabetes, osteoporosis, rheumatoid arthritis and asthma; health systems studies of governance in community services; and broad investigations of the social determinants of community well-being, including studies of social capital, cultural continuity and resilience in the Aboriginal workforce. All these studies involve Indigenous partners from planning and design through implementation and dissemination.

Our KT model is based on the principle that research users must not only participate in the research process from the beginning, but must exercise a degree of control or ownership over the research process if the results are to be seen as meaningful and useful. We engage Indigenous groups, government policy makers, program developers and providers across multiple health jurisdictions, academic disciplines and research areas in a series of workshops and meetings both to guide the research process and to ensure that potential users are familiar with the research results and their policy relevance.

Results of the KT Experience

These initiatives have fostered new social connections between university-based health researchers and First Nations health planners and led to opportunities to incorporate evidence-based decision-making in First Nations communities. Many First Nations

health planners in Manitoba have now made population health research a critical part of their health governance structures and participate in research networks dedicated to addressing health disparities in First Nations communities.

These initiatives also fostered the development of health information systems. The creation of databases derived from both health surveys and provincial healthcare utilization data has been identified as a priority by First Nations authorities, who recognize the potential for building an evidence base for policy claims on different levels of government. Previously, this initiative was important only to university-based researchers, but the push is now mainly from the First Nations community.

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The early success of the MFN-CAHR and AMC partnership has led to the development of new research space at the University of Manitoba, funded by the Canada Foundation for Innovation, and an Aboriginal Capacity and Development Research Environment grant from CIHR's Institute of

Aboriginal Peoples' Health. Both grants emphasize the need for research to be structured by a university–community partnership and for KT to be a critical aspect of all research activities. They also focus on capacity building by providing both space and resources to attract Aboriginal peoples into the health research process.

New research space and a dedicated research group have fostered new research networks, many of which have applied to CIHR to undertake studies with KT as a central component. New researchers now have access to the expertise required to establish successful research studies with Indigenous communities.

Lessons Learned

Perhaps somewhat ironically, the success of our KT activities has led to a situation where the demands for researcher involvement in the First Nations policy and planning process have outstripped the capacity of researchers at MFN-CAHR to respond. First Nations authorities in Manitoba constantly need to generate information to support their claims on federal and provincial governments for healthcare resources. Expectations are now that MFN-CAHR resources can be deployed to answer some of these questions in timely ways, but the relationship has been threatened by the reality of equally compelling, university-based demands on the researchers.

Most importantly, much KT activity is still funded at the margins of research grants. MFN-CAHR receives no dedicated funds from any agency to support KT activities. Research grants from CIHR and other funders acknowledge the need for KT, but the time and cost of these activities are rarely funded at the necessary level. Researchers, particularly in a young organization, are also mindful of the realities of advancement in the university, where traditional academic progress is rewarded over community-oriented activities.

The ownership and control of research data is also a contested area. First Nations in Canada have established a set of principles known as OCAP (ownership, control,

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access and possession of research data) that they expect to govern the relationship between researchers and First Nations communities and authorities. MFN-CAHR was instrumental in developing these principles in the late 1990s in the context of implementing the regional health survey. Similar principles were

included in the early research contracts between MFN-CAHR and the AMC, providing a foundation for the development of a trusting relationship.

Reaching agreement around OCAP principles, however, can delay and even curtail research and KT activities. In particular, “possession” of databases generated by provincial or federal data stewards is highly problematic, given confidentiality and privacy legislation. Data generated by researchers must also be protected for the privacy of research participants. Balance is required to avoid exclusionary approaches by either partner, which can foster distrust, lack of participation and conflict. The principles of mutual respect, the privacy and confidentiality of information at the individual and sub-group level and mechanisms for conflict resolution should therefore form an integral part of research agreements. Our experience suggests that when an organization such as MFN-CAHR is trusted by all partners as an appropriate data steward, then OCAP issues fade somewhat into the background. But when the capacity for ongoing KT activities is limited, this trust can be compromised.

Conclusions and Implications

The time and resources required for KT are significant, and researchers and partners need to understand both the opportunities and the limitations on this kind of activity.

Researchers also need to be appropriately supported to make this investment in terms of both funding and reward systems in the university and with partners. In addition, community partners require resources in order to engage effectively in the KT process. Successful KT, conducted on the margins of research grants, should be celebrated, but it may not be sustainable and may compromise the fundamental character of the partnership if expectations exceed capacity.

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Call to Authors

Linkage and Exchange provides a forum for knowledge translation (KT) case studies. Submissions should include an abstract of no more than 100 words, a brief statement of background and context, a description of the KT initiative, a presentation of results (including challenges that arose and how they were addressed) and a discussion of lessons learned, highlighting those that are potentially transferable to other topics and settings. Manuscripts should be a maximum of 2,000 words, excluding the abstract and references.

Appel aux auteurs

« Liens et échanges » fournit un forum pour des études de cas en application des connaissances (AC). Les articles soumis doivent comporter un résumé d'au plus 100 mots, une brève mise en contexte, une description de l'initiative d'AC, une présentation des résultats (y compris les défis qui se sont présentés et comment ils ont été relevés), ainsi qu'une discussion des leçons apprises, surtout celles qui sont potentiellement transférables à d'autres sujets et à d'autres cadres. Les manuscrits doivent être d'au plus 2 000 mots, excluant le résumé et les références.

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